

Dear Newly Diagnosed Parent,

I remember the day my then 14-month-old son Orion was diagnosed with Angelman syndrome – devastating, crushing, hopeless. I heard words that no parent ever imagines hearing about their child.

This is a point/counterpoint 4 years after diagnosis that I hope will give you hope for a future – not at all as you expected – but richer than you could ever imagine.

“Your son has Angelman syndrome.” ***I had never heard of that before diagnosis day.***

“He will never talk.” ***Orion is 5, and he has five spoken words. He uses his voice and gestures to communicate. He also uses his AAC (augmentative and alternative communication) device, which is not his preference, however, his language continues to grow and his communication abilities are maturing.***

“He will probably walk ... eventually.” ***Orion started walking at 19 months. He started running at 3 years old. He is now 5 years old and he is able to safely navigate our treacherous stairs unassisted, alternating his feet going up and coming down. He is also doing wheelbarrow, walking on his hands, up those same steep stairs, which would be hard for any 5 year old to do!***

“He will be severely intellectually disabled.” ***Orion understands everything, responds appropriately when he wants, and continues to amuse us with his wit, intelligence and charm.***

“He will continue to have seizures.” ***We have seizures under control thanks to neurofeedback and the Low Glycemic Index Treatment diet.***

“He will never have a job.” ***He is always finding creative solutions to problems. I think he may be an engineer ... or a male model because he is incredibly handsome!***

“He will have problems learning even the simplest of tasks.” ***He was potty trained at 2 years old. I know many neurotypical boys who aren't potty trained at that age.***

“He will need 24-hour-care for the rest of his life.” ***Without a meaningful therapeutic this would probably be true. But I want him to live an independent life and be able to make good decisions!***

That is why the work that FAST is doing to cure Angelman syndrome is so important. Things are not good enough the way they are now, I want so much more for Orion and he has so much more to give!

He is not his diagnosis. He is very capable. He works really hard, and we push him even harder. His smile is magnetizing, and everyone adores him. I am confident that with an effective treatment Orion could be an Olympic swimmer, or a neuroscientist, or a philosopher, or maybe all three! I can't wait to find out!

Love,
Amelia, an Angelman parent just like you